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## Are there Gender, Racial, or Relationship Differences in Caregiver Task Difficulty, Depressive Symptoms, and Life Changes among Stroke Family Caregivers?

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### Abstract

**Objective**—To examine differences in caregiver perceptions of task difficulty, depressive symptoms, and life changes based on caregiver characteristics of gender, race, and type of relationship to the person with stroke.

**Methods**—A sample of 243 stroke caregivers (females  $n = 191$ ; males  $n = 52$ ; non-African Americans  $n = 184$ ; African Americans  $n = 59$ ; non-spouses  $n = 127$ ; spouses  $n = 116$ ) were interviewed by telephone within 8 weeks of the survivor's discharge to home. Measures included the Oberst Caregiving Burden Scale (OCBS) for task difficulty, Patient Health Questionnaire (PHQ-9) for depressive symptoms, and Bakas Caregiving Outcomes Scale (BCOS) for life changes. Three general linear models computed differences in OCBS, PHQ9, and OCBS scores.

**Results**—Significant differences were found on the OCBS for females ( $p < 0.001$ ) and African American spouses ( $p < 0.048$ ); on the PHQ9 for females ( $p < 0.001$ ), non-African Americans ( $p = 0.047$ ), spouses ( $p = 0.003$ ), and African-American spouses ( $p = 0.010$ ); and on the BCOS for females ( $p = 0.008$ ), and non-African Americans ( $p = 0.033$ ).

**Conclusions**—Findings suggest that female and non-African American stroke caregivers are relatively more likely to experience task difficulty, depressive symptoms, and negative life changes

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as a result of providing care. African American spouses were also at risk. Tailoring interventions based on caregivers' characteristics may improve outcomes.

## Keywords

Stroke; Caregiver; Demographics; Burden; Depressive Symptoms; Life Changes

Stroke, a leading cause of serious disability in the United States, affects approximately 795,000 people each year [1]. Currently, 6.8 million American adults are living with the effects of stroke [1]. Although death rates are decreasing, there will be an increased incidence of persons surviving stroke and living with their disabilities over the coming years as the population ages [1]. Among Medicare patients discharged from the hospital after stroke, 45% return directly home, 24% are discharged to inpatient rehabilitation facilities, and 31% are discharged to skilled nursing facilities [2]. For those returning home, the sudden, unexpected nature of stroke coupled with a shorter average length of stay in the hospital for persons with stroke [1] often leaves family caregivers unprepared for providing care [3]. Caregivers are unprepared for the new responsibilities [4] and often experience distress prior to their family member's discharge to home [5]. Furthermore, family caregivers continue to feel the burden of caregiving and have poorer health status months after their family members are discharged home [6].

In previous studies, caregivers of persons with stroke have reported negative changes in their physical and mental health, quality of life, and finances [3, 7, 8,], as well as increased burden [9, 10] and depression [11–13] as a result of taking care of the person with stroke [3, 14, 15–17]. In Visser-Meily et al.'s [18] study, 80% of the stroke caregivers (n= 211) reported decreased quality of life and 52% reported depressive symptoms one year after their family member's stroke. Caregivers in the Bakas et al. study [19] identified difficult and time-consuming tasks, such as providing emotional support for the person with stroke ; arranging transportation; managing finances, bills, or forms related to the stroke; and carrying out household tasks such as cooking, cleaning, and laundry.

Due to the many role changes and competing demands imposed by caregiving, providing care for a family member with stroke can be very different for male versus female caregivers relative to how they handle the stress of caregiving. Similarly, caregivers' varying cultural backgrounds may affect their caregiver experiences with the person with stroke. King et al. [14] suggested that cultural differences may influence how caregivers cope with the demands of caregiving. For example, African-American caregivers commonly viewed caregiving as 'expected' versus non-African-American caregivers who 'tended to view caregiving as disrupting their lifestyle'. This suggests that researchers need to further investigate cultural differences among caregivers of persons with stroke.

The high incidence of stroke creates a need for a variety of family caregivers, such as spouses, adult children, or others. However, the types of relationships caregivers have with persons with stroke may influence the dynamics of caregiving. For example, the way in which spouses are affected by caregiving may be different from adult child caregivers, who are often struggling with conflicting demands such as work or children. Spouses usually are older and may be dealing with more of their own co-morbidities. Proportions of spouse

caregivers to adult child caregivers have been similar across studies. In Mant and colleagues' [20] study, 65% caregivers were reported to be spouses, 24% adult children, and 10.9% other. Morimoto et al.'s [21] stroke caregiver sample consisted of 70% spouses, 21% adult children, and 9% other.

Little research, however, has examined how caregiver characteristics, including gender, race, and relationship to the person with stroke are related to caregiver outcomes. Identifying caregiver characteristics of gender, race, and relationship and their interrelation with perceptions of task difficulty, depressive symptoms, and life changes may yield valuable information in designing interventions tailored to caregiver needs. The purpose of this study is to explore differences in caregiver task difficulty, depressive symptoms, and life changes based on caregiver characteristics of gender, race (non-African American vs. African American), and type of relationship (spouse vs. non-spouse) to the person with stroke.

## Methods

### Design and Procedures

A descriptive correlational design was used to explore differences in outcomes based on demographic factors using baseline data from an ongoing randomized controlled clinical trial testing the Telephone Assessment and Skill-Building Kit (TASK II) (R01 NR010388) (NCT01275495 [ClinicalTrials.gov](https://clinicaltrials.gov)). A convenience sample of 243 family caregivers of persons with stroke was recruited from eight Midwest hospitals after university IRB approval was obtained. Listed caregivers were mailed the study brochure and informed consent forms and contacted by phone by trained interviewers. Caregivers were asked to participate in the study if they met the following inclusion criteria: a) were the primary caregiver of the person with stroke; b) planned to provide care for one year or longer; c) had access to a telephone; d) were willing to participate in nine calls from a nurse and five data collection interviews; and e) the person with stroke had been discharged home no more than eight weeks before baseline data collection. Participants were excluded from the study if: a) the caregiver or the survivor's age was less than 21 years; b) the caregiver denied that the survivor had a stroke; c) the caregiver scored less than 16 on the Oberst Caregiving Burden Scale (OCBS) and/or scored less than four on the six-item Mini Mental Status Exam (MMSE) [23]; d) survivor resided in a nursing home or long-term care facility; or e) survivor or caregiver was pregnant or had a terminal illness or a history of hospitalization for alcohol or drug abuse, severe untreated mental illness, or being a prisoner or on house arrest. Informed consent was obtained during the screening process or prior to the baseline data collection. Baseline data were collected by trained interviewers using a standardized script and analyzed after verifying for accuracy in data entry.

### Instruments

**Task difficulty**—Perceived task difficulty was measured by the difficulty subscale from the 15-item Oberst Caregiving Burden Scale (OCBS)[19]. Caregivers were asked to rate the level of difficulty for the 15 items using a response scale ranging from 1 (not difficult) to 5 (extremely difficult). Evidence of content and construct validity as well as internal

consistency reliability for the OCBS has been provided in previous studies [19, 23–25]. The Cronbach alpha for OCBS difficulty subscale for this study was 0.90.

**Depressive symptoms**—Depressive symptoms were measured by the Patient Health Questionnaire (PHQ-9), a nine-item questionnaire with items ranging from 0 (not at all) to 3 (nearly every day) over the past two weeks. Total scores can range from 0 (no depression) to 27 (severe depression). Evidence of internal consistency reliability, content validity, and sensitivity have similarly been shown in other studies [24–26]. The Cronbach alpha for PHQ9 for this study was 0.77.

**Life changes**—Life changes were assessed using the 15-item Bakas Caregiving Outcomes Scale (BCOS). Caregivers were asked about life changes specifically as a result of providing care (e.g. changes in physical health, emotional well-being, level of energy, financial well-being). Each item is rated on a response scale ranging from 1 (changed for the worst) to 7 (changed for the best). Evidence of internal consistency reliability and content, criterion, and construct validity have been well documented in stroke caregiver studies [24, 27]. The Cronbach alpha for the BCOS for the present sample was 0.88.

**Survivor impairment**—The Stroke Specific Quality of Life Scale (SSQOL Proxy) was used for caregivers to provide ratings of survivor impairment. Subscales used for this study included survivor mobility, self-care, language, thinking, and personality. The questionnaire is divided into two sections. In the first section, caregivers were asked to rate survivor activities on a five-point scale ranging from 1 (couldn't do it at all) to 5 (no trouble at all). In the second section, caregivers were asked about the survivor's ability to perform various functions on a five-point scale ranging from 1 (strongly agree) to 5 (strongly disagree). Higher scores indicated less impairment. Several studies [24, 28] have shown good evidence of internal consistency reliability for the SSQOL, Proxy. The Cronbach alphas for the instrument subscales in the present sample ranged from 0.70 to 0.92.

**Demographic data**—A demographic survey assessed characteristics of the stroke caregiver and survivor such as age, gender, race, and type of relationship.

## Data Analysis

Descriptive statistics and the Cronbach alpha were used to describe the sample characteristics and research instruments. Using baseline data, three separate general linear models were computed to determine differences in task difficulty (OCBS), depressive symptoms (PHQ-9), and life changes (BCOS) based on demographic characteristics using an alpha of .05. Log transformation of the scales was conducted to achieve normality prior to analyses. Independent variables for each model were caregiver gender (male/female), relationship (spouse/non-spouse), and race (non-African-American/African-American), with interaction effects also being explored. Response differences for individual OCBS and BCOS items based on demographic characteristics were also tested using exact likelihood ratio Chi-square and odds ratios. The Benjamini-Hochberg method [29] was used to reduce the probability for Type I error by adjusting the p values for significance.

## Results

### Description of the sample and instruments

A total of 243 stroke caregivers provided baseline data for the study. Most were female (78.6%) and Caucasian (72.0%), and they were fairly evenly distributed between spouses (47.7%) and non-spouses (53.2%). Mean caregiver age was 54.2 SD 12.1 years (range 22 – 87).

All of the instruments for the study had acceptable evidence of internal consistency reliability, with alphas ranging from 0.70 to 0.92 as shown in table 2. On average, caregivers perceived tasks to be slightly to moderately difficult, and they exhibited mild depressive symptoms as measured by the PHQ-9, with average life changes being rated as “changed for the worse.” Survivor impairment on average was moderate for mobility, self-care, language, thinking, and personality using the SSQOL.

### Overall model results

Table 3 shows results for the three general linear models testing differences in task difficulty (OCBS), depressive symptoms (PHQ-9), and life changes (BCOS) based on caregiver, gender, race, and type of relationship. All three models were statistically significant.

For the model testing differences in perceived task difficulty (OCBS), caregiver gender [ $F(1,235) = 14.11$ ;  $p < 0.001$ ] and the interaction between race and relationship [ $F(1,235) = 3.95$ ;  $p = 0.048$ ] were significant. Female caregivers and African American spouses perceived relatively more task difficulty, as shown in tables 3 and 4.

For the model testing differences in depressive symptoms (PHQ-9), caregiver gender [ $F(1,239) = 26.6$ ;  $p < 0.001$ ], race [ $F(1,239) = 4.00$ ;  $p = 0.047$ ], relationship [ $F(1,239) = 6.06$ ;  $p = 0.003$ ], and the interaction between race and relationship [ $F(1,239) = 6.67$ ;  $p = 0.010$ ], were all significant. Females, non-African Americans, and spouses exhibited relatively more depressive symptoms; however, African American spouses had the highest depressive symptoms when testing for interaction effects. These results are shown in tables 3 and 4. We were unable to test race by gender interaction effects due to small cell sizes.

For the model testing differences in life changes (BCOS), caregiver gender [ $F(1,233) = 7.20$ ;  $p < 0.008$ ] and race [ $F(1,233) = 4.60$ ;  $p = 0.033$ ] were significant. Female caregivers and non-African Americans exhibited more negative life changes, as shown in tables 3 and 4.

Because perceptions of task difficulty (OCBS) and life change (BCOS) both differed by caregiver gender, post hoc item analyses were conducted to determine which tasks were viewed as most difficult and which life changes were more detrimental for female caregivers (supplementary tables A and B). Female caregivers were found to be 4.45 times more likely than males to report having difficulty with finding care for the survivor while they were away ( $p < 0.001$ ). Although there were no significant gender differences on the other OCBS items, a number of caregiving tasks were rated as moderately to extremely difficult for both male and female caregivers. For example, both male and female caregivers found household tasks (47.3%), finances (45.7%), and transportation (43.0%) as being moderately to

extremely difficult. Additional items such as providing emotional support and managing behavior problems were also difficult for over 40% of the caregivers (supplementary table A). Post hoc analyses did not yield significant gender differences in life changes (BCOS); however, many caregivers found that their time for social (63.2%) and family (58.4%) activities, financial well-being (50.6%), level of energy (46.5%), and emotional well-being (40.7%) changed for the worse.

Because non-African American caregivers experienced more negative life changes ( $p < 0.05$ ), post hoc analyses were conducted to determine which particular life changes were most problematic for these caregivers (supplementary table B). At the item level, non-African American caregivers were relatively 3.1 times more likely to experience negative change related to having time for family activities ( $X^2 = 14.5$ ;  $p < 0.001$ ). Non-African American caregivers were also 2.8 times more likely to experience negative changes in emotional well-being ( $X^2 = 9.7$ ;  $p = 0.002$ ).

## Discussion

### Task Difficulty

**Gender**—In this study female caregivers reported more task difficulty than male caregivers. These results were consistent with findings of several studies [15, 25, 30, 31]. Rombough et al.'s [30] review of four studies found that female caregivers, specifically spouses, had significantly higher perceived burden than male caregivers. Similarly, Tiegs et al.'s [31] study found that caregiver gender significantly predicted perceived caregiver burden ( $\beta = .305$ ,  $p = 0.49$ ), with female caregivers reporting higher burden and more emotional consequences resulting from providing care. Bakas et al. [25] and Ostwald and colleagues' [15] studies of spousal stroke caregivers respectively found, that female caregivers reported more difficulty with tasks and experienced higher stress in providing care for the person with stroke. Balancing additional new caregiving responsibilities with competing family obligations may contribute to female caregiver task difficulty and caregiver burden. Tiegs et al. [31] suggested that male perceptions of less caregiver burden may be due to their instrumental approach in solving problems and coping with stress.

**Race and Relationship (spouse vs non-spouse)**—Our study also found that, although there were no significant differences in perceived task difficulty based on race or relationship, there was a significant interaction between race and relationship, with African American spouses exhibiting the highest perceptions of task difficulty. Other studies, however, have reported that African Americans caregivers reported lower levels of perceived burden [14, 32]. Van Puymbroeck & Rittman [8] found caregiver burden was predicted by the caregiver's relationship to the person with stroke. They found that non-spouses perceived significantly less overall burden than spouses at one month; however, their study did not examine the interaction between race and relationship effects.

Our findings indicate the need to further explore interaction effects, and to use caution when generalizing results of the present study. Though we found that certain groups of caregivers tended to have relatively more task difficulty (a between-group difference), there were also considerable within-group differences, which suggest the need for individualized



interventions for caregivers. This might also explain why some studies have reported inconsistent results with respect to differences in perceived task difficulty, caregiver burden, type of relationship, or race.

Other possible reasons for inconsistent results in the research literature are the different measurements and operationalized definitions of caregiver burden and task difficulty. Task difficulty is defined as difficulty with respect to particular caregiving tasks such as providing personal care, managing emotions and behaviors, and interacting with health care providers. Some burden measures address stress or strain from the caregiving role in general (e.g., Caregiver Reactions Assessment (CRA) [33]; Caregiver Burden Scale (CBS) [34]; Zarit Burden Interview (ZBI), [35], whereas others address the impact of caregiving (e.g., Caregiver Coping (F-COPES), [36]; Caregiver Strain Index (CSI), [37]; Physical Caregiving Responsibility Inventory (PCRI), [38]; Perceived Stress Scale (PSS), [39] rather than difficulty with particular tasks as measured by the Oberst Caregiving Burden Scale (OCBS) [19].

### Depressive Symptoms

**Gender**—Similar to our results with task difficulty, female caregivers reported more depressive symptoms than male caregivers; findings that were consistent with previous studies [12, 25, 40]. King et al. [12] showed that female gender was a significant predictor of depression at T1 (during hospitalization), but was not significant at T2 (during home care). By contrast, in Van Puymbroeck's et al.'s [41] study of 87 persons with stroke and their caregivers, female caregivers reported fewer depressive symptoms than male caregivers. In other studies [5] caregiver gender was not a significant predictor of depression scores, nor did caregiver gender mediate the course of depression in Visser-Meily et al.'s [10] study of caregiver spouses of persons with stroke.

**Race**—Our results showed significant differences between non-African Americans and African Americans regarding depressive symptoms. Non-African Americans reported significantly more depressive symptoms than African Americans, which is consistent with several previous studies [41–44]. For example, Clay and colleagues' [42] study of 146 caregiver/survivor dyads found that non-African American caregivers exhibited relatively poorer mental health in relation to caregiver stressors. Likewise, Grant and colleagues [43] reported that non-African American stroke caregivers had a 3.7 times greater risk for depressive symptoms than African-Americans. Similarly, Van Puymbroeck et al. [41] and Wright et al. [44] found that caregiver race/ethnicity was indicative of caregiver depressive symptoms. Wright and her colleagues [44] reported non-African American stroke caregivers' depressive symptoms increased over time, whereas African American stroke caregivers' depressive symptoms decreased over time.

Caregivers' cultural backgrounds may help explain the differences in depressive symptoms based on race. King et al. [14] suggested that cultural differences may influence how caregivers cope with the demands of caregiving. For example, African-American caregivers commonly viewed caregiving as 'expected' in contrast to non-African American caregivers, who 'tended to view caregiving as disrupting their lifestyle' [14]. Additionally, it is possible

that fewer depressive symptoms reported by African-Americans may be attributed to greater spirituality. Taylor et al.'s [45] study revealed that African Americans, compared to Caucasians, demonstrated higher levels of both public and private religious behaviours, including endorsement of religious commitment (e.g. importance of religion, religious minded, religious comfort). Similarly, in Pierce's [46] study, urban African-American caregivers reported that spirituality (commitment, love, affection) resulted in feelings of well-being and helped them to feel connected and comforted during difficult times. In another study, African-American daughters reported that religion, prayer, and faith in God helped them cope [47]. The influence of cultural factors, such as spirituality, may explain why African Americans experienced less depressive symptoms in our study, and coped better in other studies. The influence of cultural factors on depressive symptoms is an important area for future research.

**Relationship (spouse vs non-spouse)**—In the current study spouses reported more depressive symptoms than non-spouses, which supports findings from Berg et al.'s [11] study (n=98), one of the few studies in the stroke literature that have compared depressive symptoms of spousal stroke caregivers to non-spousal stroke caregivers. Berg and colleagues [11] found spousal caregivers' mean depressive scores were significantly higher ( $p<0.05$ ) than those of other caregivers during the acute phase and at 6 and 18 months. Our results were also consistent with Pinquart and Sorensen's [48] findings from a meta-analysis of 168 empirical studies of spouses, adult children, and children-in-law who were caregivers of older adults with dementia. They found that spousal caregivers had higher levels of depressive symptoms than adult children and children-in-law.

**Race by Relationship**—Although African Americans as a whole had significantly lower depressive symptom scores, we found that African-American spouses had the highest level of depressive symptoms. These findings indicate the need to look beyond the main effects for race and to explore interaction effects. In Cuellar's [32] study comparing African American and Caucasian female caregivers of post-stroke adults, 78% of African American caregivers were non-spouses (47.2% daughters and 30.6% others), and 22.2% were wives. Cuellar [32] suggested that, for African American adult daughter caregivers, caregiving may be viewed more as a shared experience. As a result, African-American non-spousal caregivers may report less task difficulty, depressive symptoms, and negative life changes because caregiving responsibility for the stroke survivor is distributed among other family members. African American spousal caregivers, on the other hand, may feel that as a spouse, the responsibility of caregiving lies solely with them. Additionally, King et al. [14] found that African American spousal caregivers also reported poorer family functioning, suggesting that stroke may have disrupted family dynamics and relationships. The altered family functioning may contribute to increased depressive symptoms for spousal caregivers. The results of our study, however, should be interpreted with caution because we had small numbers of African American spouses (n=24) and African American non-spouses (n=34) for comparison.



## Life Changes

**Gender**—In our study female caregivers reported more negative life changes than males. However, results are mixed in the literature. Our results were consistent with those of Bakas et al. [25], and Larson et al. [49] but not with Peyrovi and colleagues [50]. Bakas, and colleagues [25] showed that female caregivers had significantly more negative stroke-related outcomes than male caregivers at both 1 and 4 months after stroke. Larson et al.'s [49] results were similar to our findings even though they used the Life Situation Among Spouses after the Stroke Event Questionnaire (LISS) to measure stroke caregivers' quality of life. Larson et al.'s [49] study showed that, although both genders increased their perceived general quality of life during the year, female spouses consistently reported a lower quality of life than male spouses. In contrast, Peyrovi et al.'s [50] study, which used the BCOS, did not find gender to be a significant predictor of perceived life changes.

**Race**—Non-African American caregivers in this study reported relatively more negative life changes, which is consistent with past studies [14, 32, 42]. Cuellar [32] found non-African American caregivers had lower life satisfaction scores and higher stress than African American caregivers. In the King et al. [14] study non-African American spousal caregivers were more likely to experience negative life changes and anxiety. Clay et al.'s [42] findings suggested that African American caregivers showed relatively more adaptability to negative survivor outcomes.

## Limitations

The caregiver participants were recruited from Midwest hospitals, and thus results may only be generalizable to the Midwest where there are small proportions of Hispanic stroke caregivers. We also had relatively small portions of African Americans (n=59) in the study, and therefore results should be interpreted with caution. There may also have been a self-selection bias for the caregivers who participated; caregivers willing to participate in a clinical trial may not be representative of all caregivers. Additionally, results were from data captured within eight weeks after the survivor was discharged home, which may not reflect more long-term caregiving experiences. Finally, the current study is limited because it is cross-sectional in nature, and therefore causality cannot be inferred.

## Summary and Implications

In summary, female caregivers reported more task difficulty, more depressive symptoms and worse life changes than male caregivers, particularly in terms of finding care for the person with stroke while away. Non-African American caregivers exhibited relatively more depressive symptoms and perceived worse life changes, especially in terms of changes in family activities and emotional well-being. However, there were significant race by relationship interaction effects for task difficulty and depressive symptoms, with African American spouses having the highest task difficulty and depressive symptom scores. Regardless of gender, race, or relationship, large proportions of caregivers did experience particular tasks as difficult (e.g. household tasks, finances, transportation, emotional support, and managing behavior problems) and negative life changes (e.g. time for social and family activities, financial well-being, level of energy and emotional well-being), emphasizing the

need to look beyond group differences when exploring task difficulty and life changes. Future stroke caregiver interventions are needed that are also sensitive to the caregiver's culture, gender, and relationship to the person with stroke. Future research to investigate the role of family, managing emotions, and depressive symptoms in stroke caregivers may provide additional insight into cultural variations.

## Conclusion

The findings of this study are significant because female, non-African Americans comprise the largest proportion of family caregivers in the United States, and we found this group to be having the most problems with the caregiver role. Though unique individual differences should be considered when assessing the needs of stroke family caregivers, a heightened awareness of the greater risk for negative consequences from caregiving for Caucasian female caregivers is warranted, as well as for African American spouses. In addition, further research is needed to investigate cultural and gender-based differences. Finally, further exploration of underlying factors that lead to the more positive experiences of male and African American caregivers is recommended.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## References

1. Go AS, MozaHarien D, Roger VI, Benjamin EJ, Berry JD, et al. Heart Disease and Stroke Statistics – 2013 update: A report from the American Heart Association. *Circulation*. 2013; 127:e6–e245. [PubMed: 23239837]
2. Buntin MB, Colla CH, Deb P, Sood N, Escarce JJ. Medicare spending and outcomes after postacute care for stroke and hip fracture. *Medical Care*. 2010; 48:776–784. [PubMed: 20706167]
3. White CL, Korner-Bitensky N, Rodrique CR, Sourial R, Lambert S, Wood-Dauphinee S. Barriers and facilitators to caring for individuals with stroke in the community: the family's experience. *Canadian Journal of Neuroscience Nursing*. 2007; 29:5–12. [PubMed: 18240626]
4. Lutz BJ, Young ME, Cox KJ, Martz C, Creasy KR. The crisis of stroke: experiences of patients and their family caregivers. *Topics of Stroke Rehabilitation*. 2011; 18:786–797.
5. Shanmugham K, Cano MA, Elliott TR, Davis M. Social problem-solving abilities, relationship satisfaction and depression among family caregivers of stroke survivors. *Brain Injury*. 2009; 23:92–100. [PubMed: 19191088]
6. Tooth L, McKenna K, Barnett A, Prescott C, Murphy S. Caregiver burden, time spent caring and health status in the first 12 months following stroke. *Brain Injury*. 2005; 19:963–974. [PubMed: 16263639]
7. Jonsson AC, Lindgren I, Hallstrom B, Norrving B, Lindgren A. Determinants of quality of life in stroke survivors and their informal caregivers. *Stroke*. 2005; 36:803–808. [PubMed: 15761203]
8. Van Puymbroeck M, Rittman MR. Quality of life predictors for caregivers at 1 and 6 months poststroke: results of path analyses. *Journal of Rehabilitation Research & Development*. 2005; 42:747–760. [PubMed: 16680612]

9. Rigby H, Gubitz G, Philips S. A systematic review of caregiver burden following stroke. *International Journal of Stroke*. 2009; 4:285–292. [PubMed: 19689757]
10. Visser-Meily A, Post M, van de Port I, Maas C, Forstberg-Warleby G, Lindeman E. Psychosocial functioning of spouses of patients with stroke from initial inpatient rehabilitation to 3 years poststroke: course and relations with coping strategies. *Stroke*. 2009; 40:1399–1404. [PubMed: 19095973]
11. Berg A, Palomaki H, Lonnqvist J, Lehtihalmes M, Kaste M. Depression among caregivers of stroke survivors. *Stroke*. 2005; 36:639–643. [PubMed: 15677575]
12. King RB, Carlson CE, Shade-Zeldow Y, Bares KK, Roth EJ, Heinemann AW. Transition to home care after stroke: depression, physical health and adaptive processes in support persons. *Research in Nursing & Health*. 2001; 24:307–323. [PubMed: 11746061]
13. Klinedinst NJ, Gebhardt MC, Aycok DM, Nichols-Larsen DS, Uswatte G, Wolf SL, Clark PC. Caregiver characteristics predict stroke survivor quality of life at 4 months and 1 year. *Research in Nursing & Health*. 2009; 32:592–605. [PubMed: 19722169]
14. King RB, Hartke RJ, Houle TT. Patterns of relationships between background characteristics, coping, and stroke caregiver outcomes. *Topics in Stroke Rehabilitation*. 2010:309–317.
15. Ostwald SK, Bernal MP, Cron SG, Godwin KM. Stress experienced by stroke survivors and spousal caregivers during the first year after discharge from inpatient rehabilitation. *Topics in Stroke Rehabilitation*. 2009; 16:93–104. [PubMed: 19581196]
16. McCullagh E, Brigstocke G, Donaldson N, Kalra L. Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke*. 2005:2181–2186. [PubMed: 16151029]
17. Bakas T, Scarton L. Stroke and the family. In: Stein, J.; Harvey, RI.; Macko, RF.; Winstein, CJ.; Zorowitz, RD.; Wittenberg, G., editors. *Stroke Recovery and Rehabilitation*. 2nd. Woodbridge, CT: Demos Publishing; in press
18. Visser-Meily A, Post M, Schepers V, Lindeman E. Spouses' quality of life 1 year after stroke: prediction at the start of clinical rehabilitation. *Cerebrovascular Diseases*. 2005; 20:443–448. [PubMed: 16230849]
19. Bakas T, Austin JK, Jessup SL, Williams LS, Oberst MT. Time and difficulty of tasks provided by family caregivers of stroke survivors. *Journal of Neuroscience Nursing*. 2004; 36:95–106. [PubMed: 15115364]
20. Mant J, Carter J, Wade DT, Winner S. Family support for stroke: a randomized controlled trial. *Lancet*. 2000; 356:808–813. [PubMed: 11022928]
21. Morimoto T, Schreiner AS, Asano H. Caregiver burden and health-related quality of life among Japanese stroke caregivers. *Age Ageing*. 2003; 32:218–223. [PubMed: 12615568]
22. Callahan CM, Unverzagt FW, Hui SL, Perkins AJ, Hendrie HC. Six-item screener to identify cognitive impairment among potential subjects for clinical research. *Medical Care*. 2002; 40:771–781. [PubMed: 12218768]
23. Bakas T, Burgener SC. Predictors of emotional distress, general health, and caregiving outcomes in family caregivers of stroke survivors. *Topics in Stroke Rehabilitation*. 2002; 9:34–45. [PubMed: 14523721]
24. Bakas T, Champion V, Perkins SM, Farran CJ, Williams L. Psychometric testing of the Revised 15-item Bakas Caregiving Outcomes Scale. *Nursing Research*. 2006; 55:346–355. [PubMed: 16980835]
25. Bakas T, Kroenke K, Plue LD, Perkins SM, Williams LS. Outcomes among family caregivers of aphasic versus nonaphasic stroke survivors. *Rehabilitation Nursing*. 2006; 31:33–42. [PubMed: 16422043]
26. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*. 2001; 16:606–613. [PubMed: 11556941]
27. Bakas T, Champion V. Development and psychometric testing of the Bakas caregiving outcomes scale. *Nursing Research*. 1999; 48:25–29.
28. Williams LS, Weinberger M, Harris LEA, Clark DO, Biller J. Development of stroke-specific quality of life scale. *Stroke*. 1999; 30:1362–1369. [PubMed: 10390308]
29. Benjamini Y, Hochberg Y. Controlling the false discovery rate: a practical and powerful approach to multiple testing. *Journal of the Royal Statistical Society Series B*. 1995; 57:289–300.

30. Rombough RE, Howse EL, Bagg SD, Bartfay WJ. A comparison of studies on the quality of life of primary caregivers of stroke survivors: a systematic review of the literature. *Topics in Stroke Rehabilitation*. 2007; 14:69–79. [PubMed: 17573313]
31. Tiegs TJ, Heesacker M, Ketterson TU, Pekich DG, Rittman MR, Rosenbek JC, Stidham BS, Gonzalez-Rothi LJ. Coping by stroke caregivers: sex similarities and differences. *Topics in Stroke Rehabilitation*. 2006; 13:52–62. [PubMed: 16581630]
32. Cuellar NG. A comparison of African-American & Caucasian American female caregivers of rural, post-stroke, bedbound older adults. *Journal of Gerontological Nursing*. 2002; 28:36–45. [PubMed: 11829224]
33. Given CW, Given B, Stommel M, Collins C, King S, Franklin S. The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing & Health*. 1992; 15:271–283. [PubMed: 1386680]
34. Macera CA, Eaker ED, Jannarone RJ, Davis DR, Stoskopf CH. A measure of perceived burden among caregivers. *Evaluation & the Health Professions*. 1993; 16:204–211.
35. Schreiner AS, Morimoto T, Arai Y, Zarit S. Assessing family caregiver's mental health using a statistically derived cut-off score for the Zarit Burden Interview. *Aging & Mental Health*. 2006; 10:107–111. [PubMed: 16517485]
36. McCubbin, HI.; Olson, D.; Larsen, A. Family Crisis Oriented Personal Scales (F-COPES). In: McCubbin, HI.; Thompson, AI., editors. *Family assessment: Resiliency, coping and adaptation: Inventories for research and practice*. Madison, WI: University of Wisconsin Publishers; 1981. p. 455-507.
37. Robinson B. Validation of a Caregiver Strain Index. *Journal of Gerontology*. 1983; 38:344–348. [PubMed: 6841931]
38. Printz-Fedderson V. Group process effect on caregiver burden. *Journal of Neuroscience Nursing*. 1990; 22:164–168. [PubMed: 2142189]
39. Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. *Journal of Health and Social Behaviour*. 1983; 24:386–396.
40. Alexander T, Wilz G. Family caregivers: gender differences in adjustment to stroke survivors' mental changes. *Rehabilitation Psychology*. 2010; 55:159–169. [PubMed: 20496970]
41. Van Puymbroeck M, Hinojosa MS, Rittman MR. Influence of sense of coherence on caregiver burden and depressive symptoms at 12 months poststroke. *Topics in Stroke Rehabilitation*. 2008; 15:272–282. [PubMed: 18647731]
42. Clay OJ, Grant JS, Wadley VG, Perkins MM, Haley WE, Roth DL. Correlates of health-related quality of life in African-American and Caucasian stroke caregivers. *Rehabilitation Psychology*. 2013; 58:28–35. [PubMed: 23437997]
43. Grant JS, Weaver M, Elliott TR, Bartolucci AA, Giger JN. Sociodemographic physical and psychosocial factors associated with depressive behavior in family caregivers of stroke survivors in the acute care phase. *Brain Injury*. 2004; 18:797–809. [PubMed: 15204320]
44. Wright LK, Hickey JV, Buckwalter KC, Hendrix SA, Kelechi T. Emotional and physical health of spouse caregivers of persons with Alzheimer's disease and stroke. *Journal of Advanced Nursing*. 1999; 30:552–563. [PubMed: 10499211]
45. Taylor RJ, Chatters LM, Jayakody R, Levin JS. Black and white differences in religious participation: a multisample comparison. *Journal for the Scientific Study of Religion*. 1996; 34:403–410.
46. Pierce LL. Caring and expressions of spirituality by urban caregivers of people with stroke in African-American families. *Qualitative Health Research*. 2001; 11:339–352. [PubMed: 11339078]
47. Jones-Cannon S, Davis BL. Coping among African-American daughters caring for aging parents. *Association of Black Nursing Faculty*. 2005; 16:118–123.
48. Pinquart M, Sorensen S. Spouses, adult children, and children-in-law as caregivers of older adults: a meta-analytic comparison. *Psychology and Aging*. 2011; 26:1–14. [PubMed: 21417538]
49. Larson J, Franzen-Dahlin A, Billing E, Arvin MV, Murray V, Wredling R. The impact of gender regarding psychological well-being and general life situation among spouses of stroke patients during the first year after the patients' stroke event: a longitudinal study. *International Journal of Nursing Studies*. 2008; 45:257–265. [PubMed: 17046770]

50. Peyrovi H, Mohammed-Saeid D, Farahani-Nia M, Hoseini F. The relationship between perceived life changes and depression in caregivers of stroke patients. *Journal of Neuroscience Nursing*. 2012; 44:329–335. [PubMed: 23124123]

**Table 1**

Sample Characteristics (N = 243).

Characteristics	Mean (SD) Range	f (%)
<b>Caregivers</b>		
Age	54.8 (12.1) 22–87	
Education in Years	13.7 (2.5) 7–22	
Gender		
Male		52 (21.4)
Female		191 (78.6)
Race		
African American		59 (24.5)
Caucasian		175 (72.0)
Asian		3 (1.2)
American Indian/Alaskan Native		1 (.4)
More than 1 Race		5 (2.1)
Type of Relationship to Survivor		
Spouse		116 (47.7)
Non Spouse		127 (52.3)
<b>Persons with stroke</b>		
Age	63.0 (14.1) 25–94	
Education in Years	12.8 (2.6) 4–20	
Gender		
Male		122 (50.2)
Female		118 (48.6)
Missing		3 (1.2)



**Table 2**

Research Instruments.

Measure	Items (no.)	n	M (SD)	Range	Cronbach alpha
Caregiver measures					
Task Difficulty (OCBS)	15	243	31.13 (11.52)	15 – 72	0.90
Depressive Symptoms (PHQ-9)	9	242	5.35 (4.85)	0 – 25	0.77
Life Changes (BCOS)	15	242	56.07 (10.38)	19 – 93	0.88
Survivor Impairment (SSQOL Proxy)					
Mobility	6	242	3.32 (1.06)	1 – 5	0.92
Self-care	5	243	3.65 (1.05)	1 – 5	0.86
Language	5	243	3.86 (0.99)	1 – 5	0.91
Thinking	3	240	2.69 (1.06)	1 – 5	0.70
Personality	3	243	2.79 (1.32)	1 – 5	0.85

*Note.* OCBS = Oberst Caregiving Burden Scale; PHQ-9 = Patient Health Questionnaire; BCOS = Bakas Caregiving Outcomes Scale; SSQOL Proxy = Stroke-Specific Quality of Life Scale.

**Table 3**

Significant Differences in Task Difficulty (OCBS), Depressive Symptoms (PHQ-9), and Life Changes (BCOS) based on Demographic Characteristics using General Linear Modeling.

<b>Task Difficulty (OCBS)</b>	<b>MS</b>	<b>F (df)</b>	<b>p</b>
Overall Model	0.52	3.97 (5,235)	<b>0.002</b>
Caregiver Race	1.83	0.36 (1,235)	0.552
Caregiver Gender	1.83	14.11 (1,235)	<b>&lt;0.001</b>
Relationship	0.50	3.83 (1,235)	0.052
Gender by Relationship	0.00	0.00 (1,235)	0.974
Race by Relationship	0.51	3.95 (1,235)	<b>0.048</b>
Error	0.13		
<b>Depressive Symptoms (PHQ9)</b>	<b>MS</b>	<b>F (df)</b>	<b>p</b>
Overall Model	5.07	7.85 (5,239)	<b>&lt;0.001</b>
Caregiver Race	2.58	4.00 (1,239)	<b>0.047</b>
Caregiver Gender	17.10	26.60 (1,239)	<b>&lt;0.001</b>
Relationship	3.91	6.06 (1,239)	<b>0.003</b>
Gender by Relationship	0.00	0.00 (1,239)	0.970
Race by Relationship	4.31	6.67 (1,239)	<b>0.010</b>
Error	0.65		
<b>Life Changes (BCOS)</b>	<b>MS</b>	<b>F (df)</b>	<b>p</b>
Overall Model	254.90	2.55 (5,233)	<b>0.029</b>
Caregiver Race	460.20	4.60 (1,233)	<b>0.033</b>
Caregiver Gender	719.70	7.20 (1,233)	<b>0.008</b>
Relationship	247.30	2.47 (1,233)	0.117
Gender by Relationship	146.00	1.46 (1,233)	0.228
Race by Relationship	0.30	0.00 (1,233)	0.956
Error	100.00		

*Note.* Scales log transformed to achieve normality

**Table 4**

Untransformed Means and Standard Deviations (SD) for Significant General Linear Modeling Results from Table 3.

<b>Task Difficulty (OCBS)</b>	<b><i>M (SD)</i></b>	<b><i>p</i></b>
<b>Caregiver Gender</b>		
Female	32.4 (11.3)	
Male	26.9 (11.5)	<b>&lt;0.001</b>
<b>Caregiver Race by Relationship</b>		
African American Non-Spouse	28.2 (11.9)	<b>0.048</b>
African American Spouse	35.0 (14.6)	
Non-African American Non-Spouse	31.1 (10.4)	
Non-African American Spouse	31.3 (11.5)	
<b>Depressive Symptoms (PHQ9)</b>		
<b>Caregiver Race</b>		
African American	4.6 (4.8)	<b>0.047</b>
Non-African American	5.7 (4.8)	
<b>Caregiver Gender</b>		
Female	5.9 (4.7)	<b>&lt;0.001</b>
Male	3.5 (4.9)	
<b>Caregiver Relationship</b>		
Non Spouse	5.1 (4.8)	<b>0.003</b>
Spouse	5.7 (4.9)	
<b>Caregiver Race by Relationship</b>		
African American Non-Spouse	3.3 (3.5)	<b>0.010</b>
African American Spouse	6.6 (5.8)	
Non-African American Non-Spouse	5.9 (5.0)	
Non-African American Spouse	5.4 (4.7)	
<b>Life Changes (BCOS)</b>		
<b>Caregiver Race</b>		
African American	58.4 (10.2)	<b>0.033</b>
Non-African American	55.5 (10.1)	
<b>Caregiver Gender</b>		
Female	55.5 (10.3)	<b>0.008</b>
Male	58.8 (9.2)	